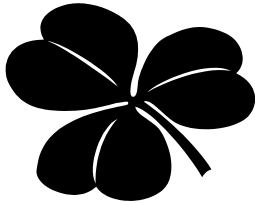


DDS' Wellness Initiative Partnership Memo



Inside this issue:

New Screening Test for CDGs	2
DMH Announces Ombudsman Services	2
Treating Adults with PKU	3
New Spanish-Language Web Site Focuses on Health	3
The Autism Learning Collaborative	4
Mental Health Task Force Update	5
Upcoming Training Opportunity for Healthcare Professionals	5
Epilepsy & Autism Training	6

DDS
Health & Wellness Section
1600 9th St., Rm. 330
M.S. 3-22
Sacramento, CA 95814

(916) 654-1859
TTY: (916) 654-2054
FAX: (916) 654-3464

Regional Centers Congratulated for Improving Oral Health

A special Oral Health Task Force meeting was held on October 9, 2003, in Sacramento. The meeting was held in conjunction with *Access California*, an honorary luncheon and awards ceremony celebrating an innovative community-based system of oral health care funded by the California Endowment.

At the meeting, Cliff Allenby, Director of the Department of Developmental Services, and Arthur Dugoni, DDS, MSD, the Dean of the University of the Pacific School of Dentistry, presented a summary of the community-based demonstration project. Awards were presented to staff of the participating regional centers: Alta California Regional Center, Central Valley Regional Center, Regional Center of the East Bay, Frank D. Lanterman Regional Center, North Bay Regional Center, Harbor Regional Center, Inland Regional Center, and San Gabriel/Pomona Regional Center. Seven of these regional centers will continue to participate in community-based projects.

Assemblywoman Lois Wolk then provided some remarks about the success of the project in her district. Other agenda items included:

- a Legislative Update by David Pisani, a Patient Advocate for

the California Dental Association; and

- an In-depth Report on the Community-based Demonstration Project by Dr. Paul Glassman & Christine Miller of the University of the Pacific School of Dentistry's Center for Oral Health for People with Special Needs.

The Oral Health Task Force is conducted by the University of the Pacific School of Dentistry and includes representatives from the Department of Developmental Services, Department of Health Services, regional centers, California Dental Hygienists' Association, and the University of San Francisco School of Dentistry. Meeting for the past five years, its main purpose is to improve the oral health of persons with developmental disabilities. This is done by promoting collaborative resource development, increasing access to dental health professionals, and providing prevention and education training to consumers, care providers, and family members.

For more information, please contact Karen Toto of the UOP School of Dentistry's Center for Oral Health for People with Special Needs, at (415) 749-3383.

New Screening Test for CDGs

Congenital Disorders of Glycosylation (CDGs) are a group of genetic conditions that alter the way affected individuals synthesize complex carbohydrates. Children with CDGs have often been mis-diagnosed for years before any alternative explanation was even suspected, sometimes only after other affected siblings were born.

Multiple types of CDGs have been identified. They predominantly cause neurological symptoms such as mental retardation, cerebral palsy, and epilepsy. Although these disorders cannot be cured (except for CDG-Ib which responds to dietary treatment), early identification can reduce many of the detrimental effects of CDGs.

CDGs should be considered in any child with mental retardation who has an unexplained multisystem disease such as failure to thrive, cerebellar atrophy, retinitis pigmentosa, peripheral neuropathy, cardiomyopathy, nephrotic syndrome, and/or excessive clotting/bleeding. Most pediatric neurologists and medical geneticists are familiar with CDG-Ia, since there have been many reports in recent literature, but it is also critical that other

physicians become aware of CDGs, especially if they take care of patients with developmental disabilities.

When compared to European centers, we are clearly under-diagnosing CDGs in this country. Fortunately, there is now a fairly reliable laboratory screening test for CDGs offered by the Mayo Clinic. The blood test is simple to order (Mayo's test code 82414 or "Carbohydrate Deficient Transferrin, Serum"), inexpensive and covered by Medi-Cal. Abnormal results should prompt primary care physicians to refer for definitive diagnosis to their local metabolic or genetic disease center.

For further information, go to the following web sites:

<http://www.cdgs.com>

http://www.burnham.org/presentations/human_glycosylation_disorders/index.htm

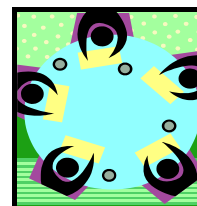
<http://www.med.kuleuven.ac.be/cdg>

Ombudsman Services Available Through the California Department of Mental Health

The California Department of Mental Health (DMH) has recently announced that Ombudsmen are available to assist persons in navigating the mental health service systems. Ombudsmen provide information on accessing mental health care and can connect people in order to resolve concerns and problems. They also connect individuals with local resources. There are problem resolution and patients' rights advocacy services in each county to assist individuals, as well.

DMH Ombudsman staff is available by phone Monday through Friday from 8 a.m. to 5 p.m. by calling (800) 896-4042, and TTY(800) 896-2512.

Phone messages are acceptable 24 hours a day, everyday. You may e-mail staff at Ombudsmn@dmhhq.state.ca.us. All calls and e-mails are confidential, and translation services are available.



Treating Adults with PKU

Approximately 1:100 residents in the State Developmental Centers (SDC) are known to have phenylketonuria (PKU) as the underlying cause of their mental retardation (MR). The figure for other Regional Centers consumers is 1:1500. This difference in rate is primarily due to the younger age of the regional center population, which has benefited from newborn screening for PKU over the past 40 years. Despite missing the opportunity for early diagnosis and treatment, which can prevent the development of MR, many other physical and behavioral complications in these older adults with PKU are still amenable to specific treatment.

A new Program Advisory to be issued by DDS on "Improving Care for Adults with Untreated PKU" reviews the traditional dietary approach of restricting phenylalanine intake and highlights several exciting new therapeutic advances. The latter include competitive inhibition of phenylalanine transport across the blood-brain barrier, and direct enhancement of enzyme activity in the liver by high-dose tetrahydrobiopterin (the natural cofactor for phenylalanine hydroxylase). Specialized community care homes for adults with mental retardation and PKU are being developed to provide a supportive environment for those whose disruptive behaviors have responded so well to dietary intervention that they are able to leave the confines of a SDC.

We have suspected that some adults born before 1966 with MR of unknown etiology may in fact have PKU. This prompted an effort to screen about 1,000 individuals from the State Developmental Centers. Although no new cases have been identified so far (results from Porterville SDC are still pending), one of the insights gained from this project is that only one-third of the known cases are on a PKU diet (ranging from 1:10 at Fairview SDC to 6:7 at Porterville SDC). Clearly, there is an opportunity for "quality improvement" in terms of increasing the percentage of adults with PKU who are benefiting from specific treatment.

Published studies (e.g., Brown & Guest, "Economic impact of feeding a phenylalanine-restricted diet to adults with previously untreated phenylketonuria", *J Intellect Disabil Res* 43:30, 1999) show that costs of treatment in a State Developmental Center setting are offset by even greater savings in terms of reduced needs for nursing care and psychotropic drugs. Whether this is true for other Regional Center consumers living in community setting remains to be demonstrated. If so, DDS can justify the screening of an additional 25,000 adults with MR of unknown etiology for undiagnosed PKU.

New Spanish-Language Web Site Focuses on Health

Information on government programs and services, as well as health and medical information, can now be found in Spanish on a new web site. This month, the federal General Services Administration launched <http://www.firstgov.gov/Espanol/index.shtml>.

The site is intended to help individuals find health information, even if they are not familiar with the arrangement of federal agencies. It is linked to over 100,000 translated government pages.

The Autism Learning Collaborative

The Department of Developmental Services, in conjunction with the Center for Health Improvement, has initiated a statewide Learning Collaborative. The goal of the Learning Collaborative is to put into practice recently published guidelines for screening, diagnosis and assessment of persons with autism spectrum disorders. The Learning Collaborative will establish regional center-directed resource networks around the state that will offer expert consultation and services on best practices for clinical evaluation of persons with autism spectrum disorders. The expected outcome is enhanced interagency collaboration and use of best practice procedures among local professionals and agencies routinely responsible for evaluating, referring and serving persons with autism.

The Learning Collaborative provides a structured problem-solving environment to identify and discuss promising change ideas, assign responsibilities for action, evaluate proposed ideas, and provide feedback on successes and barriers to efficient evaluation. The Learning Collaborative begins with a Leadership Team composed of two or three persons from each regional center within a geographic area. The Leadership Team administers a Self Assessment Tool designed to identify areas of practice and procedure that can be improved, based on best practice recommendations. The Leadership Team identifies local stakeholders, including staff from school districts, regional center vendors, community health professionals, etc., who participate in autism evaluation, assessment and referral.

The Leadership Team identifies priorities and creates Action Teams to address each priority. Each Action Team brainstorms and proposes options for improving the evaluation process and presents possible solutions to stakeholders. Proposed changes are reviewed and adopted or recommendations for change are made.

North Bay Regional Center in Napa, California, served as the prototype for developing this innovative approach to enhancing service standards. Five additional Northern California regional centers began participating in the Learning Collaborative in late October. Six Southern California regional centers joined the Collaborative in Early December. With an average statewide net increase of about 265 persons with autism per month enrolling at regional centers, the need to establish accurate, timely and uniform evaluations practices is a vital interest to everyone involved. For more information about the Learning Collaborative project, contact Ron Huff at (916) 654-1976 or Gregg Shibata (916) 930-9200.

Go to www.dds.ca.gov/autism to access *Autism Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis, and Assessment*. To order a copy call (916) 492-4000, extension 4011.

**IS YOUR REGIONAL CENTER
INTERESTED IN PARTICIPATING IN THE
LEARNING COLLABORATIVE?**

**IF SO, CALL RON HUFF AT
(916) 654-1976**

The Statewide Mental Health Task Force for Persons with Developmental Disabilities

The Statewide Mental Health Task Force For Persons With Developmental Disabilities (MHTF) meets quarterly in Sacramento. Committee members include representatives from county mental health agencies, regional centers, the Mental Health Directors Association, the Association of Regional Center Agencies, the Department of Mental Health (DMH), the Department of Developmental Services (DDS), the State Council on Developmental Disabilities, and the Tarjan Center For Developmental Disabilities at the University of California, Los Angeles.

The goal of the MHTF is to provide leadership and direction to regional centers, county mental health agencies, and service providers to assist in promoting the development of collaborative services for individuals with developmental disabilities who have mental health diagnoses.

To date, the committee has:

- created guidelines for collaboration between county mental health agencies and regional centers;
- conducted mental health/developmental disabilities training summits;
- developed a mental health planning grant proposal; and
- implemented a joint DDS/DMH Technical Assistance Team for regional centers and county mental health agencies.

Currently, the MHTF is exploring new alternatives for residential services.

Healthcare Professional Training Opportunity

The annual UCSF Update for Health Professionals in Developmental Disabilities is scheduled for March 12-13, 2004 at the Laurel Heights Conference Center in San Francisco. This program will provide a useful and practical update as well as an overview of relevant information for all health care providers who see individuals with developmental disabilities. For early registration visit the UCSF website at www.cme.uscf.edu or call (415) 476-5808.

This year's program will include the following featured lectures and special presentations:

- Epidemiology and Best Practices for Autistic Spectrum Disorders
- Update on Diagnosis and Treatment for Seizure Disorders
- Current Treatment Options for Disordered Behavior in Persons with Developmental Disabilities
- Current and Future State of the Art Neuro-imaging
- Sexual Predators, Victimization and Individuals with DD
- Legal-Ethical Dialogue Across the Life Span
- GERD, Reflux Esophagitis, Gallstones: Diagnosis and Treatment
- Special Exhibition: Life Span Resource Guides for People with Developmental Disabilities

From The Department of Developmental Services (DDS)
Health and Wellness Section
JoEllen Fletcher, Chief
1600 9th Street, Room 330, M.S. 3-22
Sacramento, CA 95814

Phone: (916) 654-2133
Fax: (916) 654-3464
Email: jfletche@dds.ca.gov

Training Announcement

The UC Davis Health System, will present training on ***Epilepsy and Autism***, March 26-28, 2004, in Sacramento. Continuing Education credit will be available to physicians, physician's assistants, psychologists, registered nurses, MFTs and LCSWs.

For further information, please contact Continuing Medical Education, UC Davis Health System at 1-866-CME4EDU (263-4338) or (916) 734-5390, or check out their web site at <http://cme.ucdavis.edu>.